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Testimony: In favor of HB 5277, An Act Concerning the Establishment of Technical Standards for Medical Diagnostic Equipment (MDE) that Promotes Accessibility in Health Care Facilities

On behalf of the disability community, especially those with mobility limitations, I would like to urge you to support HB 5277. I am in the later stages of managing an incurable muscular dystrophy that progresses steadily over time. I use a power wheelchair and I am unable to stand or transfer without assistance.

As time passes, I am losing hand dexterity, making eating and drinking near impossible without help, and—even more challenging-- handwriting is impossible and keyboarding is becoming a significant challenge

I do my best to maintain some independence and dignity, but it is very hard to do so in the medical facilities that I use because of lack of sufficient equipment to help people with mobility issues to transfer. Let me give you one recent example.

At approximately 9:45 PM On February 2nd, I had to call 911 as the result of a brain seizure. This resulted in a hospital emergency room visit where, following examination and tests, I was kept overnight, though not admitted.

On the morning of Feb 3rd, my personal care assistant (PCA) was called to bring my wheelchair to the hospital and transport me to my home.

When he arrived, the need for a portable lift to move me from hospital bed to wheelchair or vice versa, became apparent, as the room I was in was not fitted with a permanent lift system as might be expected in a properly equipped medical facility in order to meet the needs of a growing number of patients with mobility impairments. (Other emergency rooms I have used were fitted with this relatively inexpensive technology).

After some time, a portable lift was found and brought to my room. Unfortunately, without the necessary sling! After an even longer wait, a sling was located and brought to my room, (all together a delay of close to an hour! Fortunately, this was not an emergency.)

As the medical personnel tried to use the system, it became apparent to me that the incredibly well-intentioned medical staff were not adequately familiar with the transfer process. It was resolved - with guidance from my PCA, and the transfer accomplished.

Such experiences expose the patient to the risk of harm and certainly cause increased stress to an already stressful situation.